

HIV Testing History – Pre-test Version: Description and Forms Completion Instruction Sheet

This instruction sheet should be used as a guide for obtaining and recording an HIV testing history during pre-test counseling or when a client's HIV status is not yet known. It is meant to give surveillance sites that conduct HIV antibody testing an understanding of what information is needed for an HIV testing history and why it is important. The responses are used to assign an incidence estimation weight to the STARHS result.

The instruction sheet serves as a guide for obtaining an HIV testing history and for the completion of two of the forms that CDC has developed to record that information, the pre-test version of the HIV Testing History Questionnaire (Pre-test THQ) and Part D of the Program Evaluation Monitoring System (PEMS) Counseling, Testing, and Referral (CTR) Form. The PEMS CTR form is a scanable data collection tool, while the Pre-test THQ was designed to be both an interview and data collection tool. Counselors may choose to read the questions in the Pre-test THQ aloud to clients or give it to the client to complete as a self-administered questionnaire. Counselors who choose to use the Pre-test THQ as an interviewer administered tool are encouraged to develop their own personal style for asking the questions, and use the questionnaire form as a guide. The information collected here may be taken from other sources if available, and the questionnaire may be shortened accordingly. Only one question (regarding the reason for testing) must be asked as it appears on the Pre-test THQ.

This guide will demonstrate the location of each of the required pieces of information related to the client's HIV testing history on each of the CDC designed forms. Regardless of the source of the information, counselors working in CDC-funded HIV Counseling, Testing, and Referral sites located in areas funded for HIV Incidence Surveillance must record testing history information on Part D of the PEMS CTR form or use a system compliant with CDC's requirements. Counselors from non-federally funded sites should record their clients' responses on the Pre-test THQ form and return it to the jurisdiction's HIV/AIDS surveillance coordinator.

Counselors should make every effort to ensure that testing history information is complete for each client. If the Pre-test THQ is self-administered the counselor should check the questionnaire briefly after the client has completed it and attempt to clarify any questions that were left blank if possible. If the client is unwilling, or unable to answer a question upon further probing the questions should be marked "refused" or "don't know" on the questionnaire sheet by the counselor.

In the Pre-test THQ there are several varied types of font. For the purposes of the questionnaire and this instruction sheet:

instructions that explain what the question is asking and why are *printed in italics*

specific messages to the client are

set off in text boxes.

 and can be read aloud if the questionnaire is to be administered by a counselor

instructions that explain skip patterns are indicated with an arrow (⇒) and are

set off in text boxes using extra large and bold font.

Below each question from the Pre-test THQ its location on the PEMS CTR form is depicted graphically. Most of the questions appear on Part D of the PEMS CTR form except for two questions about whether the client has had a previous HIV test and a previous positive HIV test. As noted in the description of those questions and, as depicted graphically, those questions are located on Part A of the PEMS CTR form.

Instruction Sheet

The following question typically will not be asked as the counselor will be able to determine the date without input from the client. The staff use only box (#2) should be used to record the date of the HIV test if the Pre-test THQ was completed after blood for the HIV antibody test was drawn, but before the results are known, or if the HIV antibody test will be administered at some point after the Pre-test THQ is completed. The PEMS CTR form does not allow for more than one date because the CTR form is completed at the time of the HIV antibody test.

Thank you for filling out this form. Remember that all the answers you give will be kept private. Some of the answers that you give will allow you to skip some of the questions. If you are not told to go to a different question, please answer the questions in order.

PART I: Questions about your HIV tests:

1. Today's date ____/____/____ (month/day/year)

Staff use only

2. ____/____/____ Ref test date

Session Date (MM/DD/YYYY)	Site ID	Worker ID	PEMS ID <input type="checkbox"/>

The following question must be asked as written. Cognitive testing of the Pre-test THQ showed that when the order or wording of the question was changed, clients gave different answers to the question and were often confused and/or distracted by the question. The interviewer should seek "Yes" or "No" answers to the subparts of this question and should mark these responses on the form used, or have the client mark yes or no for each subpart if the counselor is using the Pre-test THQ as a self-administered questionnaire. This question is used to determine the specific reasons for testing and assists in assigning an incidence estimation weight to the STARHS result.

- 3a asks whether the client is being tested because he/she has had a recent experience (unsafe sex or injection drug use, accidental needle stick, etc.) that he/she feels put him/her at risk for HIV infection. In this case, a positive test result would be more likely to be an incident case.
- 3b asks whether the client is tested regularly (every 3 months, 6 months, yearly, etc.). It is not asking whether the test is part of routine medical care, which could mean that the client has an HIV antibody test every time he/she sees the

doctor, regardless of the interval. If the client is only testing as part of a pattern of regular testing, then the incidence estimate weight for the STARHS result would be assigned according to the length of time since the last negative test.

- 3c asks if the client has no particular reason other than to reassure him/herself (for example, some people test when they start a new relationship or have some other change in their life).
- 3d asks if the test is not the client's idea, but rather is a requirement of some other entity.
- 3e allows the client to give another reason for testing that may not have been asked (other reasons might include pregnancy or Nucleic Acid Testing (NAT)).

3. Why are you getting an HIV test today? Are you getting the test: (please check yes or no **for each question**)

- | | | |
|---|--|---|
| [a] Because you think/are worried that you might have been exposed to HIV in the past 6 months? | <input type="checkbox"/> ₀ No | <input type="checkbox"/> ₁ Yes |
| [b] Because you get tested on a regular basis (for example, once a year or every six months), and it is time for you to get tested again? | <input type="checkbox"/> ₀ No | <input type="checkbox"/> ₁ Yes |
| [c] Because you are just checking to make sure you are HIV negative? | <input type="checkbox"/> ₀ No | <input type="checkbox"/> ₁ Yes |
| [d] Because you are required to get this test by either insurance, the military, a court order, or by some other agency? | <input type="checkbox"/> ₀ No | <input type="checkbox"/> ₁ Yes |
| [e] Because there is some other reason you wanted to get tested?
If so, what is the reason? | <input type="checkbox"/> ₀ No | <input type="checkbox"/> ₁ Yes |

Reason Why Tested

First + Test

☐ Because you are concerned that you might have been exposed to HIV in the past 6 months. [01]

☐ Because you get tested routinely, and it was time for you to get tested again. [02]

☐ Because you are just checking to make sure you are HIV negative. [03]

☐ Because it was required by either insurance, the military, a court order, or for some other required reason. [04]

☐ Because there is some other reason you want to get tested. [05] (Specify)

First + Test:

Cur. Test:

☐ Don't know [99]

☐ Refused [77]

The next question is designed to provide the interviewer or client with an opportunity to skip questions that would be inappropriate for someone who is coming for his/her first HIV antibody test. If the response is “No,” or if the client is unsure or refuses to answer the question, the interviewer proceeds directly to questions regarding antiretroviral medication use. If this client’s specimen is eligible for STARHS, and the client has never

had an HIV test before, demographic and risk factor data will be used to assign an incidence estimation weight to the STARHS result. If the client has had a previous HIV test (and answers “yes” to the question below), the client’s testing history will also be considered in assigning this weight. On the PEMS CTR form the response to this question should be recorded on Part A.

4. Have you ever been tested for HIV before today?

Yes.....☐ 1

No.....☐ 0

I don't want to answer.....☐ 7

I don't know.....☐ 9

Please go to Part II: HIV Medicines on page 3

Race – Check all that apply	Race Expanded	Previous HIV Test	Self-Reported HIV Status	In HIV Medical Care
<input type="checkbox"/> American Ind. / AK Nat. [R1] <input type="checkbox"/> Asian [R2] <input type="checkbox"/> Black / African American [R3] <input type="checkbox"/> Native HI / Pacific Is. [R4] <input type="checkbox"/> White [R5] <input type="checkbox"/> Don't know [99]	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="radio"/> Yes [1] <input type="radio"/> No [0] <input type="radio"/> Don't know [9] <input type="radio"/> Refused [7] <input type="radio"/> Not asked [6]	<input type="radio"/> Positive [01] <input type="radio"/> Negative [02] <input type="radio"/> Don't know [99] <input type="radio"/> Refused [77] <input type="radio"/> Not asked [66]	<input type="radio"/> Yes [1] <input type="radio"/> No [0] <input type="radio"/> Don't know [9] <input type="radio"/> Refused [7] <input type="radio"/> Not asked [6]

Again, the following question provides the interviewer or client with the chance to skip several questions. If the client has been tested previously but has never had a positive test (which will be typical among clients who are receiving pre-test counseling), the interviewer can skip several questions that would only be appropriate if the client had tested positive at some point in the past. Clients might answer “Yes,” if they are seeking to confirm an earlier diagnosis or perhaps as a way to facilitate status disclosure to a partner. The blood from the current test is likely to be ineligible for STARHS unless their first positive test was less than 3 months ago, and a remnant specimen from that first positive test is not available for STARHS. The response to this question is recorded on Part A of the PEMS CTR form.

4a. Have you ever had a positive HIV test result?

Yes.....☐ 1

No.....☐ 0

I don't want to answer.....☐ 7

I don't know.....☐ 9

Please go to Question 4f on the next page

Client Information
Name: JAMES H. SMITH
Date of Birth: 10/10/1999
Sex: M
Race: W
Ethnicity: N

Counselor Information
Name: JAMES H. SMITH
Title: Counselor
License: 10/10/1999

Referral Information
Referral Source: JAMES H. SMITH
Referral Date: 10/10/1999
Referral Reason: JAMES H. SMITH

Counseling Session Information
Session Date: 10/10/1999
Session Time: 10/10/1999
Session Location: JAMES H. SMITH
Session Notes: JAMES H. SMITH

HW Counseling Testing and Referral Form
PART 2

For the following question, it is very important to know when the client's first positive test was conducted (i.e., when blood was drawn or when oral fluid or urine was collected). Simply asking when the person received a positive test result is not appropriate, because the client may not have returned for his or her results in a timely manner, and the date that he/she learned of the positive result may not be indicative of when he/she tested positive. The gray, "staff use only" box is included so that sites that choose to use the Pre-test THQ as an interviewer administered tool can write the first positive date here and refer back to it when asking questions later in the questionnaire. In addition, the box serves as a prompt to enter this date into the HIV Incidence Surveillance database as the date of the first positive test.

- 4b. What was the month and year of the very first time you tested positive for HIV? List when you got your test, not when you got your results. We will refer to this test date again.

____/____ (month/year)

[illegible]

The next question is asked to determine whether the client's original test report would be found in the HIV/AIDS Reporting System (HARS/eHARS). If it were, STARHS would not be performed on the client's blood from the current HIV antibody test. In addition, the

response to this question will assist in determining the weight assigned to the STARHS result when estimating incidence.

- 4c. When you first tested positive for HIV (on the date in question 4b) were you given a number or a code to use to get your results instead of your name? (check one box).

Yes..... ☐ 1
No..... ☐ 0
I don't want to answer..... ☐ 7
I don't know..... ☐ 9

First POSITIVE HIV Test

Anonymous test: ☐ Yes [1] ☐ No [0] ☐ Don't know [9] ☐ Refused [7]

Name of place tested:

Date: / (MM/YYYY) State where tested: Site type:

HIV Counseling, Testing, and Referral Form PART D

Client Name: Date:

Site:

Test Result:

Test Date:

Test Site:

Test Type:

Test Result:

Test Date:

Test Site:

Test Type:

Next, the counselor will seek the name and state of the site of the client's first HIV positive test. This question will assist in tracking the client's information in HARS/eHARS. In addition, because it is assumed that testing patterns and rate of positivity vary based on the location and type of testing facility, this question is used in the calculation of the incidence estimation weight for the STARHS result. The client should be asked to classify the type of facility if this information is not obvious from the client's response. Site type codes for the PEMS CTR form can be found on the back of Part D.

- 4d. What was the name of the place where you got your first positive HIV test? For example, this could be the name of a health clinic, blood bank, doctor's office, or STD clinic.

Site name: _____ State: _____

Staff use only
_____ Site type code

First POSITIVE HIV Test

Anonymous test: ☐ Yes [1] ☐ No [0] ☐ Don't know [9] ☐ Refused [7]

Name of place tested:

Date: / (MM/YYYY) State where tested: Site type:

HIV Counseling, Testing, and Referral Form PART D

Client Name: Date:

Site:

Test Result:

Test Date:

Test Site:

Test Type:

Test Result:

Test Date:

Test Site:

Test Type:

As with the first reason for testing question, the following question must be asked as written, and the interviewer or the client should mark each response as “Yes” or “No.” These questions are used to assign an incidence estimation weight to the STARHS result.

4e. When you got your first HIV positive test (on the date in question 4b), did you get the test: (please check yes or no **for each question**)

- | | | |
|--|--|---|
| [a] Because you thought/were worried that you might have been exposed to HIV in the 6 months before the test? | <input type="checkbox"/> ₀ No | <input type="checkbox"/> ₁ Yes |
| [b] Because you got tested on a regular basis (for example, once a year or every six months), and it was time for you to get tested again? | <input type="checkbox"/> ₀ No | <input type="checkbox"/> ₁ Yes |
| [c] Because you were just checking to make sure you were HIV negative? | <input type="checkbox"/> ₀ No | <input type="checkbox"/> ₁ Yes |
| [d] Because you were required to get the test by either insurance, the military, a court order, or by some other agency? | <input type="checkbox"/> ₀ No | <input type="checkbox"/> ₁ Yes |
| [e] Because there was some other reason you wanted to get tested?
If so, what was the reason? | <input type="checkbox"/> ₀ No | <input type="checkbox"/> ₁ Yes |

Reason Why Tested	
First + Test	Cur. Test
<input type="checkbox"/>	<input type="checkbox"/> Because you are concerned that you might have been exposed to HIV in the past 6 months. [01]
<input type="checkbox"/>	<input type="checkbox"/> Because you get tested routinely, and it was time for you to get tested again. [02]
<input type="checkbox"/>	<input type="checkbox"/> Because you are just checking to make sure you are HIV negative. [03]
<input type="checkbox"/>	<input type="checkbox"/> Because it was required by either insurance, the military, a court order, or for some other required reason. [04]
<input type="checkbox"/>	<input type="checkbox"/> Because there is some other reason you want to get tested. [05] (Specify)
First + Test:	
	Cur. Test:
<input type="checkbox"/>	<input type="checkbox"/> Don't know [99]
<input type="checkbox"/>	<input type="checkbox"/> Refused. [77]

[illegible]

Next the counselor asks when the client had his/her last HIV negative test. If the client has never tested HIV-positive before, then the last HIV negative test would be the test prior to the current test (because the client does not yet know the results of the current test). If the client has previously tested HIV positive, then he/she would provide the date of the last HIV negative test before his/her first positive test. It is important to determine when the client last had a negative test because this date will play a key role in determining the weight assigned to the STARHS result. For example, if the client received a negative result less than six months ago, and then tests positive, the probability that his/hers is an incident case is 100%, and the STARHS result is therefore given a weight of “1” in the incidence estimation.

4f. What was the month and year that you got your last negative HIV test? List when you got your test, not when you got your results.

____ / ____
month year

I have not had a negative HIV test.....☐ ⇒

Please go to Question 5

Last NEGATIVE Test	
Ever have negative test:	<input type="radio"/> Yes [1] <input type="radio"/> No [0] <input type="radio"/> Don't know [9] <input type="radio"/> Refused [7]
Name of place tested:	<div style="border: 1px solid black; width: 100%; height: 1.2em;"></div>
Date:	<div style="border: 1px solid black; width: 100%; height: 1.2em;"></div>
State where tested:	<div style="border: 1px solid black; width: 100%; height: 1.2em;"></div>
Site type:	<div style="border: 1px solid black; width: 100%; height: 1.2em;"></div>

The next question asks the name and state of the client's most recent HIV negative test. Because it is assumed that testing patterns and rate of positivity vary based on the location and type of testing facility, this question is used in the calculation of the incidence estimation weight for the STARHS result. The client should be asked to classify the type of facility if this information is not obvious from the client's response. Site type codes for the PEMS CTR form can be found on the back of Part D.

4g. What was the name of the place where you had your last negative HIV test?

Site name: _____ State: _____

Staff use only
____ Site type code

Last NEGATIVE Test	
Ever have negative test:	<input type="radio"/> Yes [1] <input type="radio"/> No [0] <input type="radio"/> Don't know [9] <input type="radio"/> Refused [7]
Name of place tested:	<div style="border: 1px solid black; width: 100%; height: 1.2em;"></div>
Date:	<div style="border: 1px solid black; width: 100%; height: 1.2em;"></div>
State where tested:	<div style="border: 1px solid black; width: 100%; height: 1.2em;"></div>
Site type:	<div style="border: 1px solid black; width: 100%; height: 1.2em;"></div>

The following question is also used to assign an incidence estimation weight to the STARHS result. The number of times tested before the current test or the first positive test is related to the likelihood that an incident case will be detected. It is important to remember that these questions are asking the number of previous tests in the two years before the current or first positive test including the current (or first positive) test and the question on the Pre-test THQ is structured in a such a way that today's test, or the first positive test is included in the count. If the current test, or the client's first positive test is the client's first HIV antibody test, then the answer to this question is "1."

5b. **For people who have NEVER had a positive test:** In the past two years, how many times did you get tested for HIV? Today's test has been included for you in this count.

1 (today's test) + ____ (tests before today) =

5a. **For people who have had a positive test before:** In the two years before your first positive test (that is, the two years before the date in question 4b) how many times did you get tested for HIV? Your first positive test has been included for you in this count.

1 (my first positive test) + ____ (tests before) =

Testing History	
First time tested: <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> (MM/YYYY)	Number of times tested for HIV in the past 2 years or in the 2 years before your first positive test: <input type="text"/> <input type="text"/>

The counselor then should determine the date of the client's first HIV test ever regardless of whether the result was positive or negative. This date is also used in calculating an incidence estimation weight for the STARHS result. There will be times when the client is unable to remember the date of the first test. In these cases, the client should be asked to estimate the date. Probes that might assist the client in remembering the date could include "think about the time of year that you had the test," or "did you have the test close to a significant event in your life, like your birthday or the beginning of a new relationship?"

6. When was the very first time you ever got tested for HIV, (when you got the test, not when you got the results)? Please make your best guess if you don't know for sure.
____ / ____ (month/year)

Testing History	
First time tested: _____ (MM/YYYY)	Number of times tested for HIV in the past 2 years or in the 2 years before your first positive test: _____

Finally, it is important to determine the client's use of antiretroviral medications. These medications can decrease the level of HIV antibodies circulating in the blood. As a result, the test used for STARHS would be less likely to detect HIV antibodies, and could therefore produce a result that suggests a recent infection regardless of the length of time since the client's seroconversion. The interviewer should have a picture (available from the state/local HIV incidence surveillance coordinator) that depicts the antiretroviral medication that a client might have taken. This card should be shown when asking about HIV medications because a client may be unsure of the exact medications that he/she has taken or may confuse other medications for antiretroviral medications and incorrectly report that he/she has taken HIV medications.

PART II: HIV Medicines

These last questions are about HIV medicines. Sometimes these are used to try to prevent HIV infection. This is called post-exposure prophylaxis, or PEP. Some of these medicines are also used to treat Hepatitis B. These medicines can also be used in HIV treatments called HAART or the AIDS cocktail. PLEASE USE THE PICTURES OF ANTI-RETROVIRAL MEDICINES ON THE LAST PAGE WHEN ANSWERING THE NEXT QUESTIONS.

7. In the past six months have you taken any medicines shown in the picture on the last page to treat or try to prevent HIV or Hepatitis?

Yes.....☐1



Please go to Question 7a

No.....☐0

I don't want to answer.....☐7

I don't know.....☐9



STOP, You are Finished

ARV or HIV Medication in last 6 months <input type="radio"/> Yes [1] <input type="radio"/> No [0] <input type="radio"/> Don't know [9] <input type="radio"/> Refused [7]		Types of Medication... <div style="display: flex; flex-wrap: wrap;"> <div style="width: 50%; text-align: center;"> <input type="text"/> <input type="text"/> <input type="text"/> </div> <div style="width: 50%; text-align: center;"> <input type="text"/> <input type="text"/> <input type="text"/> </div> </div>	Specify Other Medication... <div style="display: flex; flex-wrap: wrap;"> <div style="width: 50%; text-align: center;"> <input type="text"/> <input type="text"/> <input type="text"/> </div> <div style="width: 50%; text-align: center;"> <input type="text"/> <input type="text"/> <input type="text"/> </div> </div>	Taking any ARV or HIV medicines <input type="radio"/> Yes [1] <input type="radio"/> No [0] <input type="radio"/> Don't know [9] <input type="radio"/> Refused [7]
First day of ARV or HIV medication: <input type="text"/> / <input type="text"/> / <input type="text"/>		Last day of ARV or HIV medication: <input type="text"/> / <input type="text"/> / <input type="text"/>		

The next question is a prompt to be certain that the client has taken antiretroviral medications and to determine the type of treatment the client has received. On the PEMS CTR form codes for the medications are located on the back of Part D.

7a. Which ones did you take? Please list them. (If you are not sure of which medicines you took in the last six months, please include medicines you MIGHT have taken during that time)

ARV or HIV Medication in last 6 months <input type="radio"/> Yes [1] <input type="radio"/> No [0] <input type="radio"/> Don't know [9] <input type="radio"/> Refused [7]		Types of Medication... <div style="display: flex; flex-wrap: wrap;"> <div style="width: 50%; text-align: center;"> <input type="text"/> <input type="text"/> <input type="text"/> </div> <div style="width: 50%; text-align: center;"> <input type="text"/> <input type="text"/> <input type="text"/> </div> </div>	Specify Other Medication... <div style="display: flex; flex-wrap: wrap;"> <div style="width: 50%; text-align: center;"> <input type="text"/> <input type="text"/> <input type="text"/> </div> <div style="width: 50%; text-align: center;"> <input type="text"/> <input type="text"/> <input type="text"/> </div> </div>	Taking any ARV or HIV medicines <input type="radio"/> Yes [1] <input type="radio"/> No [0] <input type="radio"/> Don't know [9] <input type="radio"/> Refused [7]
First day of ARV or HIV medication: <input type="text"/> / <input type="text"/> / <input type="text"/>		Last day of ARV or HIV medication: <input type="text"/> / <input type="text"/> / <input type="text"/>		

The questions that follow are asked to ascertain the timeframe during which the client took antiretroviral medication. If the client is currently taking medications then the answer to the final question (the last day that medications were taken) should be the date that the testing history interview (or questionnaire) is completed.

7b. What was the first day you took any of the medicines shown in the pictures? Please make your best guess if you don't know for sure.

___/___/___ (month/day/year)

7c. Are you now taking any of the medicines shown in the pictures?

No.....☐_0



Please go to Question 7d

Yes.....☐_1

I don't want to answer.....☐_7

I don't know.....☐_9



STOP, You are Finished

7d. When was the last day you took any of the medicines shown in the pictures? Please make your best guess if you don't know for sure.

___/___/___ (month/day/year)

ARV or HIV Medication in last 6 months		Taking any ARV or HIV medicines	
<input type="radio"/> Yes [1] <input type="radio"/> No [0] <input type="radio"/> Don't know [9] <input type="radio"/> Refused [7]	Types of Medication... <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	Specify Other Medication... <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/> Yes [1] <input type="radio"/> No [0] <input type="radio"/> Don't know [9] <input type="radio"/> Refused [7]
First day of ARV or HIV medication: <input type="text"/> / <input type="text"/> / <input type="text"/>			
Last day of ARV or HIV medication: <input type="text"/> / <input type="text"/> / <input type="text"/>			